

Refresh of the National Strategic Framework for Chronic Conditions

Emerge Australia represents patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and is a trusted organisation that operates on an evidence-base with integrity and dignity. We are the only national patient organisation in Australia delivering clinical education, patient support and education, advocacy and biomedical research for those with ME/CFS and Long COVID.

ME/CFS is a highly disabling disease which affects up to 250,000 Australians, up to ten times more than multiple sclerosis (MS). The degree of impairment exceeds that of other diseases such as MS, depression and cancer.^{1,2} Twenty-five per cent of patients are bed-bound or house-bound. Seventy-five per cent of those affected are women. It can affect people of any age, background or socio-economic status. Causes of the disease remain unknown and there is no biomarker to aid diagnosis. There are no evidence-based treatment options. At best, patients manage their disease by pacing (living within the individual's energy limits) and resting to avoid exacerbation. At worst, they are prescribed harmful graded exercise therapy.

Many people with Long COVID are joining this patient cohort, with more than half of those living with Long COVID meeting diagnostic criteria for ME/CFS, which most commonly has a post-infection onset.³ Research also implies that there will be a considerable increase in the number of people with ME/CFS in the foreseeable future⁴. Emerge Australia is collecting Long COVID data (no-one else is).

Factors for Consideration in the Framework Refresh

- **Access to Centrelink/Disability Support Pension (DSP) and NDIS**

Inconsistent assessment and rejection of DSP/NDIS applications occurs due to lack of understanding (by medical practitioners and Centrelink/NDIS assessors) of ME/CFS as a permanent disability (in 90+% of cases). ME/CFS disability assessment accuracy could be improved through the development of co-designed ME/CFS and Long COVID assessment guidelines. This would reduce the number of incorrect first round assessment decisions and subsequent assessment rounds and would also help ensure timely access to support and reduce Commonwealth operating costs.

- **Expanded Medicare Items – Telehealth and Home Visits**

Rebates for complex specialist consultations, longer telehealth consults and removal of the requirement for an annual, face-to-face GP appointment for disabled chronically unwell people would assist people who are bed-bound or house-bound and unable to attend clinics. Medicare items for home visits would ensure patients receive the care they need.

- **National Post-Infection Disease Strategy**

With more than 325,000 people predicted to be affected by Long COVID and 250,000 people living with ME/CFS, Emerge Australia advocates a National Post-Infection Disease Strategy. This would ensure that post-infection diseases are addressed systematically and help ensure Australia is prepared for the long term health outcomes following the next pandemic.

¹ Kingdon, C. C., Bowman, E. W., Curran, H., Nacul, L., & Lacerda, E. M. (2018). Functional status and well-being in people with myalgic encephalomyelitis/chronic fatigue syndrome compared with people with multiple sclerosis and healthy controls. *PharmacoEconomics-Open*, 2(4), 381-392

² Nacul, L. C., Lacerda, E. M., Campion, P., Pheby, D., Drachler, M. D. L., Leite, J. C., ... & Molokhia, M. (2011). The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health*, 11(1), 1-11

³ Jason, L. A., & Dorri, J. A. (2022). ME/CFS and Post-Exertional Malaise among Patients with Long COVID. *Neurology international*, 15(1), 1-11.

⁴ Angeles, M. R., Wannan Arachchige Dona, S., Nguyen, H. D., Le, L. K. D., & Hensher, M. (2022). Modelling the potential acute and post-acute burden of COVID-19 under the Australian border re-opening plan. *BMC Public Health*, 22(1), 757.

- **ME/CFS and Long COVID: a unique opportunity**

Whilst science has not yet delivered all the answers regarding the similarities between ME/CFS and Long COVID, there are striking similarities between the diseases. With Long COVID, both due to the precise diagnostic test for the triggering virus infection that has been used and the numbers involved, we have substantial, well-defined clinical cohorts with a known virus trigger. These are available for continuing analysis with the best that modern molecular and imaging technology has to offer. This provides a unique opportunity to break open the post-infection disease story in ways that will potentially lead to better treatments and full recovery. The impact on patients with ME/CFS and Long COVID is identical, resulting in reduced quality of life, loss of independence, employment and capacity to work and loss of previous life.

With sophisticated clinical and research expertise and an excellent public health system, Australia is in a unique position to make major contributions in this complex and difficult area.

- **Share knowledge from ME/CFS research and the emerging field of Long COVID and integrate into collaborative translational research.**

Researchers have established strong links between ME/CFS and Long COVID, thereby offering opportunities for Long COVID researchers to learn from the long history of ME/CFS research. New research will be more efficient and effective if researchers don't reinvent the wheel and use findings from ME/CFS research to inform research topics, design, recruitment and analysis. Research is needed to inform diagnosis and treatment.

Progress Summary of Emerge Australia's Current Work

- Establishment of the Australian ME/CFS Registry and Biobank (in collaboration with Latrobe University).
- Expansion of the Registry and Biobank to include collection of Long COVID (the only repository in Australia) commencing in October 2023.
- Development of an ME/CFS HealthPathway that provides guidance on diagnosis and management of ME/CFS. The HealthPathway was developed in conjunction with the North-West Melbourne Primary Health Network (NWMPHN) and an accredited RACGP resource. The HealthPathway has been adopted across Victoria and we are in discussion with the Tasmanian PHN about the possibility of it being adapted and adopted across that state.

Projects being undertaken by/with other stakeholders

- Refer Appendix 1.

Issues on which Emerge Australia continues to advocate for action

- Australian clinical guidelines are outdated.
- The diagnosis and treatment of ME/CFS is confounded by the extensive range, disparity and dissimilarity of presenting symptoms.
- The cause is unknown, there is no clinically applicable diagnostic biomarker or test and no effective treatments or a cure; research is inadequately funded.
- Prognosis is therefore difficult to predict and it is unclear if ME/CFS increases mortality risk.
- Australia's clinical guidelines for ME/CFS are more than 20 years old and don't reflect current understanding of the disease, nor best practise diagnosis and management.
- Australia's Burden of Disease Study has not listed ME/CFS as a separate disease since 2003.
- There is still only a small number of GPs with ME/CFS expertise.

National Strategic Framework for Chronic Conditions

STRATEGIC PRIORITY AREAS		STATUS
Objective 1: Focus on prevention for a healthier Australia		
1.1 Promote health and reduce risk	1.1 Australians live healthy lifestyles with reduced risk of developing chronic conditions.	75% of people with ME/CFS had a post-infection onset. For those living with Long COVID, that figure increases to 100%. Contracting a virus is therefore a risk factor for ME/CFS and other long term health complications, such as postural orthostatic tachycardia syndrome (POTS). Preventing people from contracting COVID-19 and other infections is therefore the best method to reduce the risk of long-term post-infection disease.
1.2 Partnerships for health	1.2 Responsible partnerships promote health and reduce risk factors for chronic conditions.	<p>Emerge Australia partners with a range of health organisations, patients and carer representative groups and research institutes with a view to raising awareness about ME/CFS and Long COVID.</p> <p>Research</p> <p>Emerge Australia partners with a number of institutions for its ME/CFS Registry and ME/CFS Biobank. Our partners and the projects are listed in <i>Appendix 1</i>. In addition, we partner with ME/CFS research groups across Australia to help them recruit participants for their studies.</p> <p>Education</p> <p>Emerge Australia has developed two RACGP-accredited GP education modules in collaboration with ThinkGP. We have presented at General Practice Conference and Exhibition (GPCE) conferences around the country and provided education on</p>

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		<p>demand to healthcare professionals such as nurses and allied health professionals, including The Alfred Long COVID Clinic (Melbourne).</p> <p>Telehealth Services</p> <p>Emerge Australia provides Australians living with ME/CFS and Long COVID free, short-term 1:1 telehealth support. Consultations are provided by registered nurses and a social worker. Demand for this service often exceeds capacity to respond, reflecting the difficulty faced by people living with these conditions in accessing accurate information and support. Emerge Australia seeks to expand its telehealth service to meet the growing demand caused by the significant proportion of people experiencing Long COVID and meeting the criteria for ME/CFS diagnosis. We propose a hybrid funding model of MBS private billing and will seek “top-up” government funding to facilitate patient bulk-billing.</p> <p>Our focus is on stabilisation of disease severity and symptom management. A key component is educating people about pacing. This involves keeping activity levels within the available energy of the individual and guidance to reduce the risk of significant disease exacerbation.</p> <p>Partnerships with PHNs</p> <p>In collaboration with the RACGP, Emerge Australia developed an Accredited ME/CFS HealthPathway which is published on Victorian Primary Health Network (PHN) HealthPathways. We are in discussion with the Tasmanian PHN about the possibility of the HealthPathway being adapted and adopted in that state. PHNs in other states are planning to adopt and localise the HealthPathway.</p> <p>Memberships</p> <p>Emerge Australia is a member of</p> <ul style="list-style-type: none"> • Neurological Alliance Australia

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		<ul style="list-style-type: none"> • PIDA (Post Infection Disease Alliance), • Long-COVID Alliance (this one is international). • Australian COVID-19 Network which includes: <ul style="list-style-type: none"> ○ Rare Cancers Australia ○ Exercise and Sports Science Australia ○ Kidney Foundation ○ Arthritis Australia ○ Asthma Foundation ○ Heart Foundation ○ Public Health Association Australia ○ Stroke Foundation ○ University of Sydney • Thoracic Society of Australia and New Zealand • FECCA Federation of Ethnic Communities Councils of Australia • Cancer Council <p>Long COVID</p> <ul style="list-style-type: none"> • Emerge Australia is the only organisation collating data on Long COVID. • Department of Health Victoria invited Emerge Australia to present a poster at the Long COVID Conference on 1 September 2023.
1.3 Critical life stages	1.3 Australians maintain good health and healthy behaviours through times of developmental, social or environmental change.	ME/CFS and Long COVID are multisystemic conditions which affect a range of functions in the body, including cellular energy production, cardiovascular, central and autonomic nervous systems and gastrointestinal functions. Approximately 25% of people living with ME/CFS are bed-bound or house-bound. The complex and wide-ranging impact of these conditions also significantly impacts the capacity of those living with them to manage their lives.

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		<ul style="list-style-type: none"> • In addition, many living with these conditions have additional challenges such as comorbid conditions, which add to the complexity of managing their health and life. • ME/CFS and Long COVID place a strain on family relationships, both in the level of support needed and the stigma and disbelief faced by people living with these conditions. This can lead to relationship breakdown, parenting challenges and other stress, such as financial.
1.4 Timely and appropriate detection and intervention	1.4 Timely and appropriate detection and intervention reduces the risk of chronic conditions and/or disease severity	<p>Detection</p> <p>Diagnosis of ME/CFS is critical to better care and may also improve prognosis. People with ME/CFS, however, report delays in diagnosis (sometimes 5 – 10 years) and research highlights that many healthcare professionals, including GPs, lack confidence and knowledge to recognise, diagnose and manage ME/CFS as there is inadequate biomedical understanding. Both under-diagnosis and misdiagnosis are common. Delays in diagnosis impact the physical and emotional health of the person living with the condition, especially with contested diseases like ME/CFS and Long COVID. It is therefore paramount that people with ME/CFS and Long COVID receive accurate diagnosis as early as possible to ensure they are given information to try to prevent worsening of symptoms and any further deterioration of health.</p> <p>Research shows that up to 45% of Long-COVID-19 patients meet the diagnostic criteria for ME/CFS⁵ yet rates of diagnosis of ME/CFS in people with Long COVID are currently low. 89.1% of people with Long COVID experience post-exertional malaise, the hallmark symptom of ME/CFS, however only 14.7% of patients had been</p>

⁵ C. Kedor, et al. 'A prospective observational study of post-COVID-19 chronic fatigue syndrome following the first pandemic wave in Germany and biomarkers associated with symptom severity'. *Nature communications*, 13:1 (2022).

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		<p>diagnosed with ME/CFS.⁶ It is concerning that few clinicians think of ME/CFS as a diagnosis, despite the significant overlap in the diseases.</p> <p>A range of issues inhibit timely detection and appropriate/early intervention.</p> <ul style="list-style-type: none"> • Lack of awareness and initial poor health literacy (noting that patient health literacy grows significantly during the journey of diagnosis and disease management). • Stigma about the condition and lack of clinician understanding can lead to discrimination and patients being dismissed. • Australia’s ME/CFS clinical guidelines are outdated (2002) and not aligned to those of other countries and do not reflect current international best practice in clinical management of ME/CFS. <p>There is a lack of awareness of ME/CFS diagnostic criteria.</p> <p>Intervention</p> <p>While there are currently no effective, evidence-based treatments for ME/CFS and Long COVID, Emerge Australia promotes the current international best practice approach to clinical management: energy management (such as resting and pacing) and symptom management. This approach can help reduce symptom severity and improve quality of life.</p> <p><i>Clinical guidelines review</i></p> <p>Updated ME/CFS clinical guidelines are needed to speed up diagnosis and ensure that Australians living with this condition receive clinical care which is based on current evidence. Australia’s clinical guidelines have not been reviewed since 2002 and are out of line with those of other countries. The guidelines contain outdated and</p>

⁶ H. Davis, et al. ‘Characterizing long COVID in an international cohort: 7 months of symptoms and their impact’ *EClinicalMedicine*, 38:101019 (2021).

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		<p>harmful advice on activity (graded exercise therapy), cognitive behaviour therapy (CBT) and rest. Emerge Australia advocates for a review to align the guidelines with contemporary practice and diagnostic criteria in other countries, particularly the United Kingdom and USA. Australia’s out-dated guidelines continue to misinform the guidelines of other bodies. For example, the RACGP guide⁷ fails to acknowledge the second most commonly reported symptom in people with Long COVID, post-exertional malaise (PEM).⁸</p> <p>There is therefore a need to increase health literacy of health professionals and consumers about the disease and undertake research to inform diagnosis and treatment.</p>
Objective 2: Provide efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life		
2.1 Active engagement	2.1 People with chronic conditions, and their carers and families, are central to, and have an informed role in, their care management.	<p>Evidence-Based Information</p> <p>People with ME/CFS and other post-infection diseases face barriers accessing evidence-based information. It is critical that ME/CFS and Long COVID patients are empowered to understand their unique needs and become partners in their own care.</p> <p>Emerge Australia’s strategy for raising awareness of ME/CFS care management is multifaceted. It targets not only carers and families but also treating practitioners; we collaborate with medical research institutions to further develop the evidence base for ME/CFS and manage the national data collection.</p> <p>We also operate the Australian ME/CFS and Long COVID/PASC (AusME) Registry and Biobank which are patient-centred and collect vital data and biospecimens to</p>

⁷ RACGP. 'Patient resource: Managing post-COVID-19 symptoms', available at: <https://www.racgp.org.au/clinical-resources/covid-19-resources/patient-resources/patient-resource-managing-post-covid-19-symptoms/introduction> (2022).

⁸ Davis, HE, Assaf, GS, McCorkell, L, et al. 'Characterizing long COVID in an international cohort: 7 months of symptoms and their impact', *EClinicalMedicine* 38 (2021) 101019.

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		<p>support medical research discoveries for those living with ME/CFS and Long COVID (also known as post-acute sequelae of COVID-19 or PASC). Carers and supporters of those with ME/CFS and Long COVID are also able to participate as healthy controls and are a critical part of research.</p> <p>Support of carers and families of people with ME/CFS and Long COVID</p> <p>People who care for those living with ME/CFS and Long COVID face a range of challenges, especially due to the stigma and lack of awareness and understanding of these conditions. We proactively engage with carers and families of those living with ME/CFS to provide support and information both about the conditions as well as avenues for support, such as, the NDIS, Disability Support Pension and Carer Allowance.</p> <p>People with ME/CFS struggle to access these necessary supports which means that carers also have little or no support. For example, some patients live with a bucket by their bedside in which to urinate and defecate if they do not have energy to access the bathroom.</p> <p>We support carers to learn about the realities of the disease and cope with the demands of caring. Often carers are unsupported as the treating practitioner lacks understanding of the condition and how to treat it, so cannot provide support or advice to carers. Patients and carers face barriers to accessing evidence-based information and integrated non-clinical support, all of which can inhibit symptom management and recovery. It is critical that ME/CFS and Long COVID patients are empowered to understand their unique needs and become partners in their own care.</p> <p>Pivotal to care management is our support of carers, particularly those who care for patients who are bed-bound.</p>

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2.2 Continuity of care	2.2 Australians receive consistent, holistic, coordinated care across the health system to manage their chronic conditions.	<p>People with ME/CFS and post-infection diseases do not routinely receive appropriate, coordinated shared care. A major obstacle to this in Australia is the clinical guidance available to health practitioners: the outdated Australian ME/CFS clinical guidelines, and the RACGP HANDI guide “Exercise for CFS” (which is based on a Cochrane Systematic Review⁹ and is currently being contested, as well as the discredited PACE trial¹⁰). Both of these clinical guidelines promote the use of exercise as treatment for the condition despite this not being supported by evidence and this treatment posing risk of harm to patients.</p> <p>However, Optimal Care Referral Pathways (OCRPs) support integrated shared care across the entire health system. Such innovative approaches to the coordination of non-clinical service delivery have achieved improved outcomes for patients in other settings and lend promise for ME/CFS and Long COVID.</p> <p>General Practitioners cannot meet all care and support needs for patients with chronic disease. As is common with other diseases, shared care between specialist and primary care or other health professionals leads to better outcomes. Lack of access to evidence-based information and integrated non-clinical support inhibits symptom management and recovery. Development of an Optimal Care Referral Pathway would place people with ME/CFS at the centre of care decisions</p> <p>Consistent, holistic and coordinated care requires funding. General practitioners rarely offer coordinated care, often do not bulk bill and people with ME/CFS are often unable to choose their medical practitioners, least of all practitioners who understand ME/CFS (as the pool across Australia is minimal). Many people with ME/CFS are on</p>

⁹ Larun, L, Brurberg, KG, Odgaard-Jensen, J & Price, JR. ‘Exercise therapy for chronic fatigue syndrome’ *Cochrane Database of Systematic Reviews*, (2019).

¹⁰White, P. D., Goldsmith, K. A., Johnson, A. L., Potts, L., Walwyn, R., DeCesare, J. C., ... & Sharpe, M. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet*, 377(9768), 823-836.

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		<p>low incomes and frequently reliant on social security payments to survive. With the reduction in bulk billing rates, many are unable to afford healthcare, which compounds their health difficulties.</p> <p>ME/CFS is experienced as a permanent disease by most patients however people with ME/CFS are often not accepted on their first NDIS or DSP applications as a lack of understanding of the condition leads to an inconsistent approach to ME/CFS assessment by Centrelink and NDIS. In the many years (often) in which patients are seeking a diagnosis, they are not eligible to apply. Barriers to access include:</p> <ul style="list-style-type: none"> • Getting the paperwork from various health practitioners is unaffordable. • There are few specialists who understand ME/CFS. • Medical practitioners do not understand that ME/CFS is predominantly a permanent disease and disability. <p>Emerge Australia provides a template to assist formulation of an DSP application and where to seek specialist input and how to traverse the process.</p>
2.3 Accessible health services	2.3 People with chronic conditions have equitable access to quality health care.	<p>People with ME/CFS and Long COVID do not have equitable access to quality health care because of</p> <ul style="list-style-type: none"> • lack of understanding of the disease • lack of diagnostic biomarkers and tests • outdated treatment guidelines • its invisible disabling characteristics. <p>As a result, people living with these conditions often experience discrimination and mistreatment from health practitioners. In addition, those who are house-bound or bed-bound, or who live in rural or remote areas, have limited access to healthcare as they can't physically get to a clinic.</p>

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		Enhanced access to telehealth and home visits is needed for those who are bed-bound or house-bound, along with updated clinical guidelines and research to inform diagnostic testing.
2.4 Information sharing	2.4 Effective sharing of consistent, relevant and secure health information and data improves service delivery performance and health outcomes.	<p>Emerge Australia is responsible for sharing knowledge of ME/CFS and Long COVID with a range of stakeholders, through our website, health practitioner education, fact sheets, position statements and monthly research digest. There is a lack of understanding across the Centrelink, NDIS and health systems.</p> <p>Our AUSME/CFS Registry and Biobank, robust customer relationship management (CRM) system, website, IT systems for data sharing and communications systems comply with the Australian Privacy Act (1988), Victorian Health Records Act (2011) and other legislation governing data. We have in place systems for obtaining informed consent to share information, including de-identified data (which we have shared with the Department of Health).</p>
2.5 Supportive systems	2.5 Systems work together to better meet the needs of people with chronic conditions.	<ul style="list-style-type: none"> • Emerge Australia recently incorporated a Social Worker into our telehealth team to better support people living with ME/CFS and Long COVID. • The inclusion of patient navigation programs that support vulnerable people living with energy-limiting conditions like ME/CFS and Long COVID to access health and disability systems is not occurring. • HealthPathways based on current understanding of ME/CFS and Long COVID are needed across Australia. • Neither ME/CFS nor Long COVID have been assigned to a medical specialty, most likely due to the multisystemic nature of these conditions. Specialists who understand these conditions are needed to ensure that the people living with them receive the best care for their complex health.

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		<ul style="list-style-type: none"> • There is no evidence-based treatment for ME/CFS or Long COVID. There is an urgent need for funding for translational research, to build the evidence-base for potential treatments. • We are in the process of developing an Online Learning System for people living with ME/CFS and Long COVID, providing them with an opportunity to learn about their condition and self-management, in a tailored, self-paced online environment. There will be a world first. • Establishment of a health professional network would support our work and better assist patients. It will also help us educate health professionals as to best practice approaches, and establish a peer support network, to help health professionals learn from each other.
Objective 3: Target priority populations		
3.1 Aboriginal and Torres Strait Islander health	3.1 The disparity in health outcomes due to chronic conditions between Aboriginal and Torres Strait Islander people and non-Indigenous Australians is reduced.	<p>The lack of funding for ME/CFS research over many decades means there are large gaps in our understanding of prevalence, prognosis and mortality. Given high percentage of people with Long COVID who meet diagnostic criteria for ME/CFS, the prevalence of ME/CFS is expected to rise in the coming years. Up to 90% of people with ME/CFS are thought to be undiagnosed or misdiagnosed.^{11,12,13}</p> <p>Research shows that people from minority groups and lower socio-economic status have as high, or higher, prevalence rates of ME/CFS, than middle class white people.¹⁴ Despite this, research studies continue to largely include only white people. Unfortunately there is no data on the prevalence of ME/CFS or Long COVID in Aboriginal and Torres Strait Islander populations.</p>

¹¹ Committee on the Diagnostic Criteria for ME/CFS. 'Beyond Myalgic Encephalomyelitis'.

¹² M. Reyes, et al. 'Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas' *Arch Intern Med*, (2003).

¹³ Jason. 'A community-based study of chronic fatigue syndrome'.

¹⁴ S. Kamaldeep, et al. 'Chronic fatigue syndrome in an ethnically diverse population: the influence of psychosocial adversity and physical inactivity' *BMC Medicine*, 9:26 (2011).

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		<p>Given the dearth of research into ME/CFS, lack of medical profession understanding and poor history of accessing a diagnosis, there is a lack of prevalence data generally.</p> <p>Up-to-date statistics are essential to enable Australia’s health and social care systems to support ME/CFS patients. The Australian Institute of Health and Welfare (AIHW) does not collect data on ME/CFS.</p> <p>Our resources need to be translated into First Nations (and other) languages to raise awareness and develop cultural understandings of ME/CFS.</p> <p>We seek to engage better with Aboriginal Community Controlled Organisations to enhance understanding of the disease. In the meantime, we use a tick list of the twenty-two most common symptoms with First Nations peoples.</p>
3.2 Action and empowerment	3.2 Community empowerment and targeted action improves local and population health outcomes for priority populations at risk of, or with, chronic conditions.	<p>Twenty-five per cent of ME/CFS patients are house or bed-bound. Innovative approaches such as self-management/care, environmental medicine and nutrition offer pathways for patients to increase control and build hope.</p> <p>To be empowered people with ME/CFS require consistent and ongoing support so that they can build their best quality of life with care management that is individually tailored.</p> <p>People living with these conditions rely on the patient community, both in terms of support, but also information about ME/CFS and Long COVID and how to access or navigate services. Emerge Australia facilitates that through our social media accounts and our online community. We also seek to promote support groups around the country.</p>



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		<p>For targeted action, we are using GP education to encourage GPs to screen at-risk individuals, especially those who have had an infection. Early intervention of pacing can help improve long term prognosis.</p> <p>We also consider the social determinants of health and view the whole person and their carer/family members so that we can support them to address all aspects of their lives including movement, mental health, social isolation, healthy body, relationships, family, employment/income security, legal, loss/grief, self-care, information about ME/CFS and Long-COVID-19.</p>

Appendix 1

Emerge Australia’s Research Partners and Projects – As at August 2023						
State of Aust.	Researchers	Project Title	Institution	Emerge Australia Registry User	Emerge Australia Biobank User	Current Status
ACT	Brett Lidbury & Alice Richardson (Mason Foundation Collaborators)	ME Biomarker Discovery via Machine Learning	Australian National University	X		Current 2021-26
NSW	Sara Ballouz	Symptoms, mechanisms and sex: Exploring the sex differences in ME/CFS through integrated computational analyses	Garvin Institute of Medical Research	X	X	Current 2021-24
NSW	Ben Heng And Gilles Guillemin (Mason Foundation Collaborator)	New directions for early diagnosis of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: a large-scale longitudinal analysis of multiple biomarkers to find a prognostic “fingerprint”	Macquarie University	X	X	Current 2020-25
QLD	Zack Shan	Multimodal MRI of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome	Thompson Institute, University of Sunshine Coast	X		Current 2023-28
VIC	Paul Fisher (Lead CI, Mason Foundation Collaborator)	Are mitochondrial function and associated cell signalling pathways similarly affected in different Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) cohorts?	La Trobe University	X	X	Current 2021-26
VIC	Sarah Annesley (Mason Foundation Collaborator)	Better Blood Biomarkers for ME/CFS	La Trobe University	X	X	Current 2021-2024
VIC	Ken Walder	Understanding myalgic encephalomyelitis/chronic fatigue syndrome and discovering new treatments through repurposed pharmaceuticals	Deakin University	X	X	Data analysis 2021-26
VIC	Lee Hamilton	Can dietary supplementation with krill-oil improve ME/CFS symptoms?	Deakin University	X		Current 2023-25

Emerge Australia's Research Partners and Projects – As at August 2023

State of Aust.	Researchers	Project Title	Institution	Emerge Australia Registry User	Emerge Australia Biobank User	Current Status
VIC	Christopher Armstrong (Mason Foundation Collaborator) & Jane Fielding	Identifying objective behavioural markers of deficit in patients with myalgic encephalomyelitis/chronic fatigue	University of Melbourne and Monash University	X		Data analysis 2021-2023
VIC	Kegan Moneghetti	PARsing Post-exertional malaise: does post exertional autonomic recovery (PAR) impact post exertional malaise	Baker Heart and Diabetes Institute	X		Current 2021-25
VIC	Paul Gooley (Mason Foundation Collaborator), Christopher Armstrong (Mason Foundation Collaborator), Elisha Josev (Mason Foundation Collaborator), Sarah Knight, Adam Scheinberg	SPOT-ME: Serial Paediatric Omics Tracking in Myalgic Encephalomyelitis	Murdoch Children's Research Institute	X	X	Current 2021-2024
WA	Christopher Latella, Janet Taylor, Tony Blazeovich	Investigation of motor neurone firing behaviour and associations with symptom severity in individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).	Edith Cowan University	X		Current 2023-2024